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HIV in Adolescents and Young Adults

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Module 6: Key Populations
Lesson 2: HIV in Adolescents and Young Adults

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Introduction

Background

Adolescence and young adulthood is a period of intense physical and developmental transition that is characterized by experimentation and self-discovery.[1] This time period may pose unique challenges for the prevention and treatment of HIV.[2] Adolescents and young adults with HIV in the United States primarily represent two distinct groups based on when and how they acquired HIV: (1) those who acquired HIV through perinatal transmission and now have reached the age of adolescence or young adulthood, and (2) those who acquired HIV during adolescence or young adulthood through sexual contact or drug use.[3,4] In the United States, since the contemporary perinatal HIV transmission rate has been reduced to less than 1% of pregnancies in women with HIV, most adolescents and young adults living with HIV have acquired HIV through sexual contact or drug use.[2] This Topic Review will address routine care for adolescents and young adults with HIV, adolescent sexuality and reproductive health, transitioning from adolescent to adult care, and HIV preexposure prophylaxis (PrEP).

Definition of Adolescents and Young Adults

In the Centers for Disease Control and Prevention (CDC) surveillance reports, adolescents are defined as persons 13 to 19 years of age and young adults are defined as persons 20 to 24 years of age, unless otherwise specified.[5] In addition, the Adult and Adolescent ART Guidelines also define adolescents as persons 13 to 19 years of age and young adults as persons 20 to 24 years of age.[2] The antiretroviral recommendations for adolescents and young adults are based on the sexual maturity rating (SMR) of the individual.[2,6](Table 1)

Epidemiology of HIV in Adolescents and Young Adults

Adolescents and Young Adults Living with Diagnosed HIV

The Centers for Disease Control and Prevention (CDC) reports on the number of persons diagnosed with HIV in the United States, which includes all persons who have been diagnosed with HIV and are still living, regardless of when the diagnosis of HIV was made.[5] At year-end 2021, there were 28,056 adolescents and young adults (age 13 to 24 years) living with diagnosed HIV in the United States, which comprised a small fraction (2.6%) of the total number of adolescents and adults living with diagnosed HIV in the United States (Figure 1).[5] Among the individuals 13 to 24 years of age living with HIV in 2021 in the United States, 23,768 (85%) were 20 to 24 years of age.[5]

New HIV Diagnosis in Adolescents and Young Adults

The CDC also reports on the number of new HIV diagnoses each year, and this reflects individuals with a new positive HIV test during the year, but the individual may have acquired HIV long before the diagnosis of HIV was made.[5] In the year 2021, adolescents and young adults accounted for a substantial proportion (19.3%) of all adolescents and adults with newly diagnosed HIV during that year (Figure 2).[5] Among these new HIV diagnoses in the 13 to 24 age group, 5,460 (79%) were in young adults (ages 20 to 24 years).[5]

Sex (Assigned at Birth)

The Centers for Disease Control and Prevention HIV surveillance report provides data about sex assigned at birth (male or female). In the year 2021, for the 28,056 persons aged 13 to 24 years of age living with diagnosed HIV in the United States, 22,576 (80%) were male and 5,480 (20%) were female.[5] Among those newly diagnosed with HIV in 2021 in the United States, 6,098 (88%) were male and 829 (12%) were female.[5]

Transmission Categories

The following summarizes HIV transmission category data in the United States for adolescents and young adults, which are reported by assigned sex at birth (Figure 3).[5] For adolescents and young adult males living with diagnosed HIV in 2021, 85% acquired HIV through male-male sexual contact, and 8% acquired HIV through perinatal infection.[5] For adolescents and young adult females living with diagnosed HIV in 2021, 48% acquired HIV through heterosexual contact, and 40% acquired HIV through perinatal infection.[5] Among adolescents and young adult males with newly diagnosed HIV in 2021, 93% acquired HIV through male-male sexual contact, whereas 86% of females of this age group with new HIV diagnoses acquired HIV through heterosexual contact.[5]

Race/Ethnicity

Among the 28,051 adolescents and young adults living with diagnosed HIV in the United States in 2021 for whom race/ethnicity data was known, 15,733 (56%) were Black youth, 6,756 (24%) Hispanic youth, and 3,623 (13%) White youth.[5] In 2021, among the 6,927 adolescents and young adults with a new HIV diagnosis, 3,697 (53%) were Black youth, 1,854 (27%) were Hispanic youth, and 971 (14%) were White youth.[5]

Testing, Linkage to Care, and Retention in Care

CDC HIV Testing Recommendations for Adolescents and Young Adults

Since 2006, the CDC has recommended opt-out HIV testing for all persons 13 to 64 years of age, unless the local prevalence of undiagnosed HIV infection has been documented to be less than 0.1%.[7] Accordingly, routine HIV screening should include adolescents and young adults. Testing should be performed annually (or more frequently) for individuals at higher risk of acquiring HIV—defined by the CDC as persons who use injection drugs (and their sex partners), persons who exchange sex for money or drugs, sex partners of persons with HIV, and men who have sex with men, or heterosexual persons who themselves or whose sex partners have had more than one sex partner since their most recent HIV test.[7] Suboptimal HIV testing rates in vulnerable youth at risk of HIV acquisition translate into missed opportunities for HIV prevention and HIV treatment in these youth.

HIV Risk and HIV Testing Rates

In the United States, multiple sources and studies have shown that many adolescents and young adults regularly engage in sexual activity that could place them at risk of acquiring HIV. Data from the Youth Risk Behavior Surveillance System has demonstrated that among high school students in 2019, 38.4% reported having sexual intercourse at least once, 27.4% were sexually active, 45.7% reported condomless sex at last intercourse, and 8.6% reported having had 4 or more lifetime sex partners.[8] This same report noted that 9% of students who had sexual contact with a person of the opposite sex were tested for HIV, and 13% of students who had sexual contact with persons of the same or both sexes were tested for HIV.[8] In a retrospective analysis of 1,313 adolescents and young adults aged 13 to 24 years seen in 2 urban primary care clinics in Philadelphia, investigators reported that only 55% of visits for an acute sexually transmitted infection episode were associated with a completed HIV test.[9]

Knowledge of HIV Status

Based on estimates from CDC surveillance data and estimates in 2021, adolescents and young adults with HIV have the highest percentage of persons unaware of their HIV diagnosis among any age group—44% of them were unaware of their HIV diagnosis; by comparison, among all people with HIV in 2021, an estimated 12.7% were unaware of their HIV diagnosis (Figure 5).[10,11]

Barriers to HIV Testing in Adolescents and Young Adults

The reasons for the discordance between HIV risk behavior and HIV testing rates in youth are myriad and include lack of knowledge about HIV risk, lack of perceived risk, sense of invulnerability to disease, lack of access to (or awareness of) free and confidential HIV testing sites, stigma, and misconception that parental consent is required for HIV testing.[12,13,14] Additional HIV testing barriers that have been identified are lack of medical provider awareness that CDC HIV testing recommendations include testing of adolescents and young adults, lack of medical insurance, and overall limited engagement with health systems.[15] Educating pediatricians and primary care medical providers about HIV testing recommendations for adolescents and young adults has the potential to increase HIV testing, especially given that a private physician’s office or other clinic site is still the most likely setting for adolescents and young adults to get HIV testing, with fewer than 5% undergoing HIV testing at a designated HIV testing site (Figure 6).[13,15] In Connect to Testing and Prevention Services, a demonstration study conducted by the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN), investigators concluded that universal HIV screening of adolescents and young adults may play an important role in reducing stigma, but this approach may not adequately reach populations, such as youth of color, at high risk for acquiring HIV.[16] Further, they found a community-based, targeted HIV testing approach was more effective than routine screening for sexual minority males aged 13 to 24 years.[16]

Factors Impacting Linkage and Engagement in Care

For persons diagnosed with HIV, linkage to care within 30 days of diagnosis and retention in HIV clinical care are associated with improved clinical outcomes, decreased mortality, and decreased HIV transmission to sex and injecting drug partners.[17,18] Although significant research has been conducted on interventions to improve linkage to care for persons newly diagnosed with HIV, few studies have included adolescents and young adults. Therefore, the individual and structural barriers for linkage to care and engagement in HIV care that are unique to adolescents and young adults remain poorly defined. Adolescents and young adults with HIV may struggle to navigate complex medical systems, especially as they transition from pediatric to adult health centers; during this transition, many adolescents and young adults lack full autonomy as they remain dependent on their families for health insurance, transportation, housing, and other needs.[17] For those young adults who are diagnosed with HIV while on a parental insurance plan, inadvertent disclosure of their HIV status may occur. Adolescents and young adults who are members of racial, ethnic, gender, or sexual minorities may face additional stigma. In addition, receiving an HIV diagnosis during the vulnerable period spanning adolescence and early adulthood can lead to higher rates of depression and anxiety that may serve as barriers to engagement in care.[17]

Strategies for Improving Linkage to Care and Retention in Care

Interventions to improve engagement along every step of the HIV care continuum include the following: adolescent-targeted (or adolescent-friendly) services include providing dedicated adolescent-only office hours; screening for sexually transmitted infections (of genital and extragenital sites); providing condoms and hormonal contraceptives; offering preexposure prophylaxis and nonoccupational postexposure prophylaxis; connecting to peer educators and adolescent support groups; and linkage to care specialists and intensive case management.[19,20,21]

HIV Care Cascade/HIV Care Continuum

Limited data exist regarding the HIV care cascade (or HIV care continuum) outcomes in adolescents and young adults in the United States.[22,23,24] In a sample of 1,411 adolescents and young adults with HIV aged 12 to 24 years at 13 United States urban HIV care centers as part of the SMILE collaborative project, 75% were linked to care, 59% were engaged in care, 34% were actually retained in care, and only 12% had suppressed HIV RNA levels.[24] In 2021 end-of-year estimates based on CDC surveillance data, among persons with HIV 13 to 24 years of age, the overall rates of virologic suppression were only 37%, and the overall cascade of care numbers for all ages was lowest in the 13 to 24 year age group. (Figure 7).[22] Unfortunately, there is a relative lack of data on the needs of adolescents and young adults with HIV, and more research is needed to develop optimal strategies for engaging, diagnosing, and managing this population.[19,25]

Clinical and Laboratory Monitoring

Baseline Evaluation for Newly Diagnosed Adolescents or Young Adults

For an adolescent or young adult newly diagnosed with HIV, the goals of the initial evaluation are the same as for adults and are outlined by the Adult and Adolescent ART Guidelines: confirm the diagnosis of HIV, obtain a complete medical history, perform a physical examination, obtain relevant laboratory data, screen for sexually transmitted infections (at genital and extragenital sites of exposure), screen for mental health and substance use disorders, provide education about HIV, address reproductive health concerns, and link to appropriate primary care resources if necessary.[26,27] For younger adolescents, additional psychosocial intervention and additional education may be necessary, and this should ideally involve the parents or guardians, though this depends on multiple factors, including state law, institutional policy, maturity of the adolescent, and social situation. The initial evaluation of persons newly diagnosed with HIV is discussed in detail in the Initial Evaluation Lesson in the Basic Primary Care module.

Routine Monitoring

Routine laboratory and clinical monitoring of adolescents and young adults with HIV is the same as for adults with HIV and is outlined in the antiretroviral therapy guidelines.[28]

Antiretroviral Therapy for Adolescents with HIV

Initiating Antiretroviral Therapy for Adolescents and Young Adults

All adolescents and young adults with HIV should receive antiretroviral therapy, regardless of their CD4 cell count or HIV RNA level.[2] Adolescents or young adults who acquired HIV via perinatal transmission have typically been on antiretroviral therapy for many years prior to reaching adolescence and often have more complex antiretroviral regimens as a result of antiretroviral resistance mutations that accumulated over the many preceding years of receiving antiretroviral therapy.[29,30,31] All youth who acquire HIV as an adolescent or young adult should start on antiretroviral therapy (if they are not already receiving it).[2] Prior to initiating antiretroviral therapy, the clinician should assess for adherence issues and screen for mental health and substance use disorders.[2] In addition, reproductive health issues should be addressed prior to starting antiretroviral therapy, including contraception, drug interactions between antiretrovirals and oral contraceptives, pregnancy intention or planning, preexposure prophylaxis for seronegative partners, and safer sex techniques to prevent transmission of HIV or other sexually transmitted infections.[27] Standard baseline laboratory testing, including an HIV drug resistance genotype, should be ordered prior to starting antiretroviral therapy.

Choosing Antiretroviral Therapy Regimens

The selection and dosing of antiretroviral medications for adolescents is based on sexual maturity rating rather than on age. The recommended antiretroviral regimens for initial therapy for post-pubescent adolescents whose sexual maturity rating is IV or V, and for all young adults, are the same as the Adult and Adolescent ART Guidelines (Table 2).[27,32] For pre-pubescent adolescents with sexual maturity ratings between I and III, see separate Pediatric ART Guidelines in the Lesson HIV in Infants and Children.[6]

Special Considerations for Persons of Childbearing Potential

For individuals who may become pregnant, their antiretroviral regimen should be designated as a preferred regimen for use during pregnancy.[33,34,35] Based on updated data, dolutegravir is now recommended as a preferred medication for use during pregnancy and for persons trying to conceive, regardless of age.[34]

Laboratory Monitoring after Starting Antiretroviral Therapy

Routine laboratory and clinical monitoring of adolescents and young adults after starting antiretroviral therapy is the same as for adults with HIV and is outlined below.[28,36] The following summarizes recommendations in the Adult and Adolescent ART Guidelines for monitoring HIV RNA levels and CD4 cell counts after starting antiretroviral therapy:

- **HIV RNA Monitoring**: All individuals initiating antiretroviral therapy should have a baseline HIV RNA level and a repeat level obtained 2-8 weeks after initiating therapy. Subsequently, HIV RNA levels should be repeated every 4-8 weeks until the viral load is suppressed. Once HIV RNA levels are suppressed, monitoring should be done every 3-4 months. For adherent patients who have consistently suppressed HIV RNA levels and stable immunologic status for more than 1 year, HIV RNA monitoring can be extended to 6-month intervals. If a patient has a change in clinical status or has to initiate therapy with chronic corticosteroids or chemotherapy, the HIV RNA levels should be checked every 3 months.
- **CD4 Cell Count**: All persons starting on antiretroviral therapy should have a baseline CD4 cell count and a repeat value 3 months after starting therapy. During the first 2 years on antiretroviral therapy, the CD4 cell count should be monitored every 3-6 months. After 2 years on antiretroviral therapy, for adherent patients who have consistently suppressed HIV RNA levels, the frequency of CD4 cell count monitoring can be based on CD4 cell count: (1) if the CD4 count is less than 300 cells/mm^3, monitoring should continue every 3-6 months, (2) if the CD4 count is consistently in the 300 to 500

cells/mm^3 range, monitoring can be extended to 12-month intervals, and (3) if the CD4 count is consistently greater than 500 cells/mm^3, monitoring may then be considered optional. If a patient has an increase in HIV RNA, a change in clinical status, or has to initiate therapy with immunosuppressive medications, such as corticosteroids, biologics, or chemotherapy, the CD4 cell count should be checked every 3-6 months.

Adherence with Antiretroviral Therapy

Challenges with Adherence with Antiretroviral Therapy

As a group, adolescents and young adults with HIV struggle with adherence more than their adult counterparts and have lower rates of viral suppression and higher rates of viral rebound.[37] Multiple studies have identified several important barriers to antiretroviral medication adherence for adolescent populations, including depression, disruption of daily routine, poor understanding of the importance of adherence, denial and fear, forgetfulness, comorbid mental health diagnoses, substance use, lack of family and social support, and structural barriers such as homelessness.[2,38,39,40] In a study of adherence in youth (aged 12 to 24 years) with either perinatal HIV acquisition ("perinatal group") or HIV acquisition through sexual activity or drug use, the two groups in the study had many overlapping adherence challenges but also had distinct reasons for having problems with adherence.[39] "Forgetting" to take the medication was by far the most common adherence barrier in both groups.[39]

Adherence Monitoring in Adolescents and Young Adults

The Pediatric ART Guidelines recommend assessing adherence at every visit and addressing strategies that optimize adherence at every visit. This approach should utilize evidence-based approaches for adherence monitoring, including monitoring of HIV RNA levels and one additional method.[41](Table 3)

Strategies for Improving Antiretroviral Adherence in Adolescents

Whenever possible, adolescents should be placed on a once-daily antiretroviral regimen with a low pill burden that has a low likelihood of causing side effects.[2,6]& In some studies, reminder systems, such as cell phone calls, alerts, and text messaging, have been found to be particularly effective for adolescents and young adults.[2,39] Studies that have evaluated the usage of mobile phone and text messaging interventions to assist with medication adherence have found mixed results, depending on the measured outcome and the specific technology that was used.[42,43,44,45] In general, technologies involving two-way communication seemed to yield better antiretroviral adherence outcomes compared to stand-alone short message service (SMS) text message reminders.[44,45] The Centers for Disease Control and Prevention (CDC) has a free adherence resource—Every Dose, Every Day (E2D2) Toolkit; this resource includes an online site and mobile app that tracks adherence, provides appointment reminders, provides peer support and other interventions. A multi-pronged approach may prove more fruitful if it combines medication-specific adherence tactics, such as decreasing pill burden, with health care provider-oriented strategies that include supportive, emotional, or behavioral strategies for youth living with HIV. The Pediatric ART Guidelines provide strategies for improving adherence that are focused on initial intervention strategies, medication strategies, and follow-up intervention strategies (Table 4).[41]

HIV Preexposure Prophylaxis (PrEP) for Adolescents

The use of HIV preexposure prophylaxis (PrEP) is an important prevention strategy for persons who are at high risk of acquiring HIV, with several landmark clinical trials demonstrating safety and efficacy in preventing HIV acquisition in men who have sex with men (MSM) and in men and women in heterosexual HIV-serodifferent couples.[46,47,48,49,50] Most of these trials included a significant proportion of young adults aged 18 to 24 years in the patient population enrolled, but very few included adolescents (18 years of age or younger). The U.S. Public Health Service issued clinical practice guidelines for the use of HIV PrEP in May 2014, and these guidelines were updated most recently in 2021.[51] The CDC recommendations for the use of HIV PrEP in adolescents and young adults are based on a weight greater than 35 kg (77 pounds), not on a specific age.[51] Planning for the potential use of HIV PrEP in adolescents requires an infrastructure for the coordinated delivery of HIV prevention services for adolescents, including are needed that include HIV testing programs that link youth at-risk for acquiring HIV to HIV PrEP services if they test negative for HIV.[16,52]

Recommendations for Preexposure Prophylaxis in Youth

For young adults aged 18 to 24 years who are at risk of acquiring HIV, the guidelines for HIV PrEP are the same as for adults at risk for acquiring HIV.[51] Because large randomized studies of HIV PrEP did not involve persons younger than 18 years of age, there is no formal guidance regarding the use of HIV PrEP in persons under the age of 18 years. Nevertheless, based on findings from clinical trials in adults, three medications have been FDA-approved for HIV PrEP in persons without HIV who weigh at least 35 kilograms (77 pounds): oral tenofovir DF-emtricitabine, oral tenofovir alafenamide-emtricitabine, and long-acting injectable cabotegravir.[48,51,53,54,55] These medications are FDA-approved to prevent sexual acquisition of HIV, but note that tenofovir alafenamide-emtricitabine has not been FDA-approved for persons at risk of acquiring HIV through receptive vaginal sex.[51] It is important to emphasize that HIV PrEP for adolescents and young adults at risk of acquiring HIV should not be restricted based on age but instead should be determined by a weight of at least 35 kg (77 pounds).[51] For a detailed discussion of HIV PrEP, see the lesson HIV Preexposure Prophylaxis, which is in Module 5 of this curriculum.

Major PrEP Studies in Adolescents and Young Adults

Two major trials have been conducted examining the safety and efficacy of tenofovir DF-emtricitabine for HIV PrEP in adolescents and young adults in the United States.

- ATN 110**: The Adolescent Trials Network 110 (ATN 110) study enrolled 400 adolescent males (aged 18 to 22 years who have sex with other males) between March and September 2013.[56] Using tenofovir diphosphate levels in dried blood spots as a marker for adherence with PrEP, the investigators concluded there was a major decline in adherence at week 24.[56] The rates of STIs were high at baseline (22% of participants) and remained high throughout the study.[56]**
- ATN 113**: The Adolescent Trials Network 113 (ATN 113) study enrolled 260 adolescent males living in the United States, aged 15 to 17 years, who have sex with other males.[57] In this study, open-label use of tenofovir DF-emtricitabine for HIV PrEP was found to be safe and well-tolerated, but adherence to PrEP, based on tenofovir diphosphate levels in dried blood spots, decreased markedly over time during the study (Figure 8).[57] The HIV seroconversion rate was 6.4 per 100 person-years.[57]**

Legal Issues Related to HIV PrEP and Minors

All states and the District of Columbia permit minors to consent for testing and treatment of sexually transmitted infections without parental consent, and many explicitly designate HIV as a sexually transmitted infection in the law with respect to parental consent.[58] In addition, 9 states have laws that provide minors with broad authority to consent to any health care service or procedure, but these state laws have different

age cutoffs and criteria (e.g., homelessness, living separate or apart from parents, and/or managing their own financial affairs) for minors to be granted this authority.[58] No states have a law that prohibits a minor from granting autonomous consent for preexposure prophylaxis. From a practical standpoint, it may be very difficult for a minor to maintain the confidentiality of their receipt of HIV PrEP from their parents (if they are on the parent's health insurance plan), since many states allow medical providers to disclose the minor's treatment information to the parents, and billing services often include information in the explanation of benefits and specific charges that would reveal receipt of HIV PrEP clinical services and medications for HIV PrEP.[58]

Immunizations for Adolescents with HIV

General Principles for Vaccine Administration in Youth with HIV

The Advisory Committee on Immunization Practices (ACIP) publishes separate annual guidelines for the use of vaccines in children and adolescents (birth to 18 years) and for adults (age 19 and older), with both guidelines including routine immunization schedules based on medical and other conditions.[59,60,61,62] The following discussion provides additional details for some of the immunizations in adolescents and young adults. All inactivated vaccines are considered safe to administer to adolescents and young adults with HIV, irrespective of immune status. The ACIP recommends that all adolescents with HIV through 18 years of age should receive most vaccines per standard recommended (or catch-up) schedules, with the following major exceptions:[60,61]

1. Precaution should be used when administering rotavirus vaccine,
2. The measles-mumps-rubella (MMR) and varicella vaccines are contraindicated if the CD4 percentage is less than 15 or the CD4 count is less than 200 cells/mm^3, *and*
3. Modified dosing schedules are required for *Haemophilus influenzae* type b, pneumococcal conjugate and polysaccharide, meningococcal ACWY, and human papillomavirus (HPV) vaccines.

Human Papillomavirus (HPV) Vaccine

The ACIP recommends routinely administering a 3-dose series of the 9-valent HPV vaccine (9vHPV) for all males and females with HIV who are aged 11 to 26 years; the series may be started as early as 9 years of age (and should be started at age 9 in children with a history of sexual abuse or assault).[61] All adolescents and young adults with HIV should receive the 3-dose 9vHPV vaccine series, regardless of the age when the HPV vaccine series is started.[60,61,63] For pregnant individuals who have not received a complete HPV immunization series, the vaccine series initiation (or series completion) should be deferred until after pregnancy.[59]

Influenza

Annual inactivated influenza vaccine is recommended for all adolescents and young adults, including those with HIV and regardless of CD4 cell count.[59,60,61,62] The recombinant influenza vaccine should not be administered to persons younger than 18 years of age. The live attenuated influenza vaccines should not be administered to any person with HIV.[61,62]

Meningococcal ACWY Vaccine

There are two quadrivalent meningococcal conjugate vaccines (MenACWY) that are licensed and currently available for use in the United States: MenACWY-CRM, and MenACWY-TT.[64] These vaccines all provide protection against infection with the meningococcal serotypes A, C, W-135, and Y.[64] The MenACWY-TT or MenACWY-CRM can be used; ideally, the same product should ideally be used for all doses.[60,61,64] Routine meningococcal vaccination, as well as booster doses every 5 years, is recommended for all persons living with HIV, since they are at increased risk for invasive meningococcal disease.[64] The primary vaccination series for individuals with HIV requires a 2-dose initial series, with the doses given at least 8 weeks apart.[64,65]& The following summarizes meningococcal ACWY vaccine booster dose recommendations for adolescents and young adults with HIV.[61,64,65]

- If the initial meningococcal series was administered prior to age 7 years, then the first booster dose should be given 3 years after completing the primary series, and then subsequent booster doses are given every 5 years.
- If the individual was age 7 years or older when the primary series was given, then the first booster dose should be given 5 years after the primary series was completed, and then subsequent booster

doses should be given every 5 years.

Meningococcal B Vaccine

The serogroup B conjugate meningococcal vaccine is considered an optional vaccine for healthy youths 16-23 years of age, and giving the vaccine should be based on shared decision-making; if given, the preferred age range is 16-18 years.[59,60,66] There are no specific recommendations for the administration of meningococcal B vaccine for persons with HIV infection.[61,62] The ACIP recommends administering the meningococcal B vaccine to all persons 10 years of age and older, with or without HIV, who have increased risk of meningococcal B disease (e.g. persistent complement component deficiencies, anatomic or functional asplenia, or receipt of a complement inhibitor, such as eculizumab or ravulizumab).[66,67] Two meningococcal B vaccines are available: MenB-FHbp and MenB-4C. The ACIP does not give preference for one vaccine over the other, but the same vaccine must be used for all doses in the vaccine series. For persons with HIV, the dosing schedule for MenB-FHbp is a 3-dose series administered at 0, 1-2, and 6 months) and for MenB-4C, a 2-dose series should be administered at least 1 month apart.[61,66] The MenB vaccine should be avoided during pregnancy unless the individual is at increased risk of meningococcal infection. Persons should receive one booster dose of the MenB vaccine 1 year after completing the initial vaccine series, followed by booster doses every 2 to 3 years if there is a persistent risk of meningococcal infection.[61]

Pneumococcal Vaccine

Adolescents 13 to 18 years of Age: The following summarizes ACIP pneumococcal vaccine recommendations for youths with HIV who are 13-18 years of age.[61,62] Note that in August 2023, the ACIP updated and revised the 2023 annual recommendations with recommendations to include the use of 15-valent pneumococcal conjugate vaccine (PCV15) and 20-valent pneumococcal conjugate vaccine (PCV20) in children and adolescents.[68]

- If neither PCV13, PCV15, or PCV20 has been received previously, administer 1 dose of PCV20 or 1 dose of PCV15; if PCV15 is used, it must be followed by one dose of 23-valent pneumococcal polysaccharide vaccine (PPSV23) at least 8 weeks later, unless this vaccine has already been given. No further doses are required.
- For adolescents who have an incomplete PCV vaccination status, administer 1 dose of PCV20 or 1 dose of PCV15; if PCV15 is used, it must be followed by one dose of PPSV23 at least 8 weeks later, unless this vaccine has already been given.

Young Adults 19-24 Years of Age: Young adults who have not previously received pneumococcal immunization should receive immunization upon entry into care, regardless of CD4 cell count.[62] For detailed information on pneumococcal vaccine in adults, including immunization of adults with prior PCV13 or PPSV23, see the Pneumococcal section in the lesson on Immunizations in HIV, which is in Module 2.

- No prior PCV13, PCV15, or PCV20: Administer a single dose of PCV20 or PCV15; if PCV15 is used, it must be followed by one dose of PPSV23 at least 8 weeks later, unless this vaccine has already been given. Subsequently, no further doses of pneumococcal vaccine are needed.
- For young adults who have an incomplete PCV vaccination status, administer 1 dose of PCV20 or 1 dose of PCV15; if PCV15 is used, it must be followed by one dose of PPSV23 at least 8 weeks later, unless this vaccine has already been given.

Varicella Vaccine

Because the varicella vaccine is a live attenuated vaccine, adolescents and young adults with HIV should not receive this vaccine if their CD4 count is less than 200 cells/mm^3.[69] The following summarizes recommendations for administering varicella vaccine to nonimmune adolescents and young adults.

- Adolescents and young adults without evidence of varicella immunity and who have a CD4 count of 200 cells/mm^3 or greater should receive two doses of the single-antigen varicella vaccine administered subcutaneously, 4 to 8 weeks apart.[70] If more than 8 weeks elapse after the first vaccine dose, the second dose should be administered without restarting the schedule.[71]
- All adolescents and young adults who receive the varicella vaccine should be instructed to return promptly for evaluation if they develop a varicella-like rash following receipt of the vaccine.[69]

Adolescent Sexuality, Gender, and Reproductive Health

Sexual Activity

Adolescence is often a period of heightened sexual and drug activity, which has significant implications for adolescents and young adults with HIV and for those at risk of acquiring HIV.[72] In general, individuals who acquired HIV as an adolescent or young adult had an earlier onset of sexual activity than similarly aged adolescents and young adults who acquired HIV perinatally.[29,72,73]

- **LEGACY Study**: The Longitudinal Epidemiologic Study to Gain Insight into HIV/AIDS in Children and Youth (LEGACY) evaluated 752 adolescents and young adults (aged 13 to 24 years) with HIV at 22 clinics in the United States and found that a significantly higher percentage of youth who acquired HIV as an adolescent or young adult were sexually active when compared with youth who acquired HIV perinatally (89.5% versus 34.1%), and had higher rates of sexually transmitted infections (32.1% versus 10.3%).[72]
- **Adolescent Medicine Trials Network**: In the Adolescent Medicine Trial Network (ATN), investigators analyzed cross-sectional survey data between 2009–2012 collected from youth with HIV aged 12 to 26 years from 20 sites; there were 2,198 youth participants, including 649 with perinatally-acquired HIV and 1,547 with HIV acquired HIV as an adolescents or young adult.[74] Youth who acquired HIV as an adolescent or young adult had a higher number of recent sex partners and more episodes of condomless sex with serodifferent partners when compared with those who acquired HIV from perinatal transmission (Figure 10).[74]

Screening for Sexually Transmitted Infections

All adolescents and young adults with HIV should undergo screening for sexually transmitted infections, according to the 2021 STI Treatment Guidelines.[75] These guidelines recommend screening for sexually transmitted infections in all sexually active persons with HIV at the initial HIV care visit and at least annually thereafter, with more increased screening based on the presence of ongoing risk factors and the prevalence of sexually transmitted diseases in the community.[75] Specific screening should be performed at genital and extragenital sites for curable sexually transmitted diseases (e.g., syphilis, gonorrhea, and chlamydia).[75] For those with ongoing sexually transmitted infection risk, screening (at genital and/or extragenital sites of exposure) is recommended once every 3 to 6 months.[75]

Contraceptive Management

Sexually active adolescent and young adult women with HIV should have access to the same array of contraceptive options as older women with HIV, including hormonal contraception (e.g., pill, ring, injection, or implant) and intrauterine devices (IUDs). Significant drug interactions can occur between hormonal contraceptives and certain antiretroviral medications; these interactions are detailed in the Adult and Adolescent ART Guidelines in the table on Drug Interactions Between Antiretroviral Agents and Hormonal Contraceptives.[35] The CDC has published the U.S. Medical Eligibility Criteria for Contraceptive Use (US MEC), which provides specific guidance regarding hormonal contraceptive use for women at high risk of acquiring HIV.[76] These guidelines take into consideration the available data related to HIV acquisition or transmission associated with hormonal contraception use and the benefits of preventing unintended pregnancy. A full discussion of contraceptive management for HIV in persons with HIV is available in a separate Topic Review HIV in Women in the Key Populations module.

Sexual Minority Adolescents and Young Adults With HIV

Gay, bisexual, and other young men who have sex with men (YMSM), particularly young Black MSM, have a disproportionate burden of HIV in the United States.[2,77] Information on gender identity is not consistently collected or documented in current HIV surveillance systems, but studies have reported a high HIV prevalence

among transgender persons (approximately 20 to 30%), particularly among transgender women.[78,79,80] Sexual and gender minority adolescents and young adults with HIV are more likely to have a lower education level, lower perceived risk, and lower levels of family and social support, as well as structural barriers to accessing healthcare, such as discrimination and decreased access to identity-affirming health care clinics and providers.[81]

Special Considerations for Youth with Perinatal HIV

Informing Children and Adolescents of Their HIV Status

For children who have acquired HIV perinatally, the timing of informing them of their HIV status is a highly sensitive and complicated issue. Studies of youth who acquire HIV perinatally found 10 years of age was the typical time for informing a youth of their HIV status, which is older than for many other chronic conditions.[72] The LEGACY study that included 571 youth with perinatally-acquired HIV found that 32% of those aged 13 years and older were unaware of their HIV status, and 25% of those unaware of HIV status were sexually active.[72] Lack of knowledge of HIV status as a young person who is entering adolescence is problematic and has obvious implications for HIV transmission.[72,82] The American Academy of Pediatrics strongly encourages the disclosure of HIV to school-aged children and states that adolescents should know their HIV status and be informed about the potential outcomes of their health behaviors (including sexual activity).[83]

MENTAL HEALTH

Adolescents and young adults who acquired HIV perinatally have higher rates of mental health disorders compared with peers without HIV, as shown in one study that found a 12-month psychiatric disorder prevalence of nearly 70% among adolescents and young adults with HIV (or with a history of exposure to HIV).[84] An extensive literature review further confirmed the high prevalence rates of psychiatric disorders in youth with HIV.[85] According to a review of 8 small studies involving youth with HIV (who acquired HIV perinatally), the most common mental disorders were attention deficit hyperactivity disorder (28.6%), anxiety (24.3%), and depression (25%).[86] Youth with perinatally-acquired HIV may also have high rates of behavioral, developmental, and neurocognitive disorders.[87,88] Anxiety, depression, substance use, and post-traumatic stress disorder are common among youth with HIV who acquired HIV as an adolescent or young adult.[89]

Transitioning to Adult Care

Transitioning from Adolescent to Adult Care

Adolescents and young adults with chronic diseases, including HIV, may face a difficult time in transitioning from adolescent to adult health care settings. The transition may be complicated by several different factors, including the presence of coexisting developmental or psychosocial delays, attachment to pediatric/adolescent providers, difficulty trusting a new provider, adjustment to an adult care setting that typically has less psychosocial support and allows less time per encounter, insurance and financial issues, and a lack of communication between pediatric and adult providers.[2,12,25,90,91,92] Medical providers and institutions transition youth to adult clinics at different ages (some at age 18, some at age 21, and some at age 24 or 25), so the maturity of the transitioning adolescent/young adult often varies in different health care settings. Adolescents with perinatal HIV may struggle with additional burdens, such as the loss of a parent to HIV and stigma relating to their HIV diagnosis.[90,91] Because of these many factors, there is often a high rate of attrition, and potentially an increase in mortality among adolescents with HIV as they transition from the pediatric/adolescent multidisciplinary care setting to the adult medical care setting.[91,93]

Models of Transition to Adult Care

The concept of health care transition, which has been defined as the purposeful, planned movement of children with special health needs from child-centered to adult-centered care, is a relatively new frontier for HIV medicine, since children with HIV did not typically survive to adulthood prior to the availability of effective antiretroviral therapy.[90,92,94] Researchers have found that an organized, deliberate, developmentally appropriate, and compassionate process of medical care transition can improve outcomes as adolescents and young adults enter adult care settings.[25,95] Adolescents and young adults should be included in the conversations around transition, as there are clear discrepancies between what adolescents and young adults need and expect from their medical environment and what they experience (Table 5).[96] Various facilitators to a successful transition have been identified, such as developing a relationship with the new adult provider prior to the actual transition, educating adult HIV care teams about transition, developing an individualized transition plan, and providing a formal written transition document. [2,25,90,91,95] There are, however, no evidenced-based guidelines or models to inform the type of transitional care that should be provided to adolescents and young adults with HIV.

Summary Points

- The HIV epidemic among adolescents and young adults encompasses two very different populations: those who acquired HIV perinatally and those who acquired HIV as adolescents or young adults through sex or injection drug use.
- In the United States, adolescents and young adults comprise only about 3% of all persons living with diagnosed HIV, but they make up about 19% of adolescents and adults newly diagnosed with HIV.
- Male youths living with HIV predominantly acquire HIV via male-to-male sexual contact, whereas female youth acquire HIV mostly through heterosexual contact.
- HIV testing rates are low among adolescents and young adults, and about 2 out 5 youth with HIV do not know their HIV status.
- All adolescents and young adults with HIV should receive antiretroviral therapy, both for their own health benefit and to reduce the risk of HIV transmission to others.
- Antiretroviral therapy selection and dosing for adolescents and young adults is based on their sexual maturity rating rather than on age.
- For adolescents and young adults who have a sexual maturity rating of IV or V, the antiretroviral regimen recommendations are the same as for adults.
- Concerns about barriers to adherence with adolescents should not exclude youth from receiving antiretroviral therapy, but should prompt extra effort to prepare youth for starting antiretroviral therapy and to support adherence while on treatment.
- Most adolescents and young adults with HIV are sexually active, with higher rates of sexual activity reported among those who acquire HIV as adolescents compared with those who acquired HIV perinatally.
- Researchers have found that an organized, deliberate, culturally competent, developmentally appropriate, and compassionate process of transition can improve health outcomes as adolescents and young adults enter adult care settings, which is essential for their continued engagement in HIV.

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Figures

Figure 1 Persons Living with Diagnosed HIV, by Age Group, United States, Year-End 2021

Source: Centers for Disease Control and Prevention. Diagnoses of HIV infection in the United States and dependent areas, 2021. HIV Surveillance Report, 2021; vol. 34. Published May 2023.

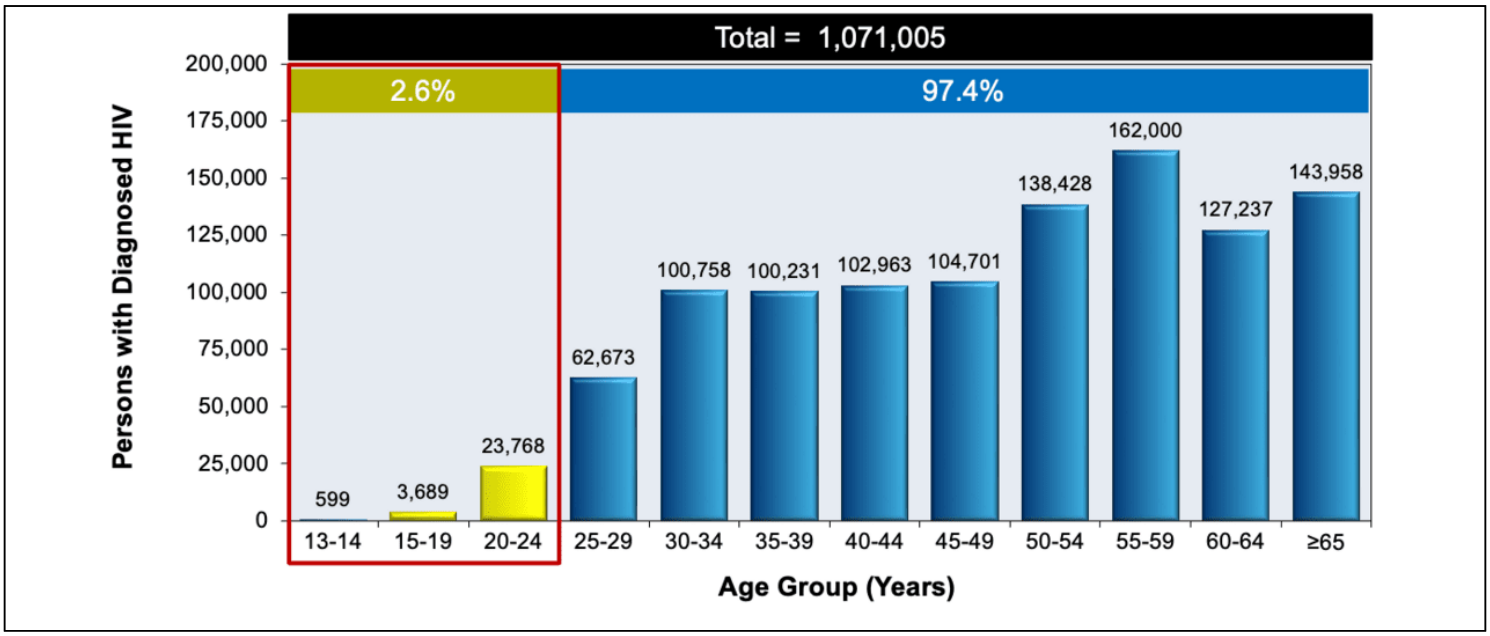

Figure 2 New HIV Diagnoses in United States by Age Group at Time of Diagnosis, United States, 2021

Source: Centers for Disease Control and Prevention. Diagnoses of HIV infection in the United States and dependent areas, 2021. HIV Surveillance Report, 2021; vol. 34. Published May 2023.

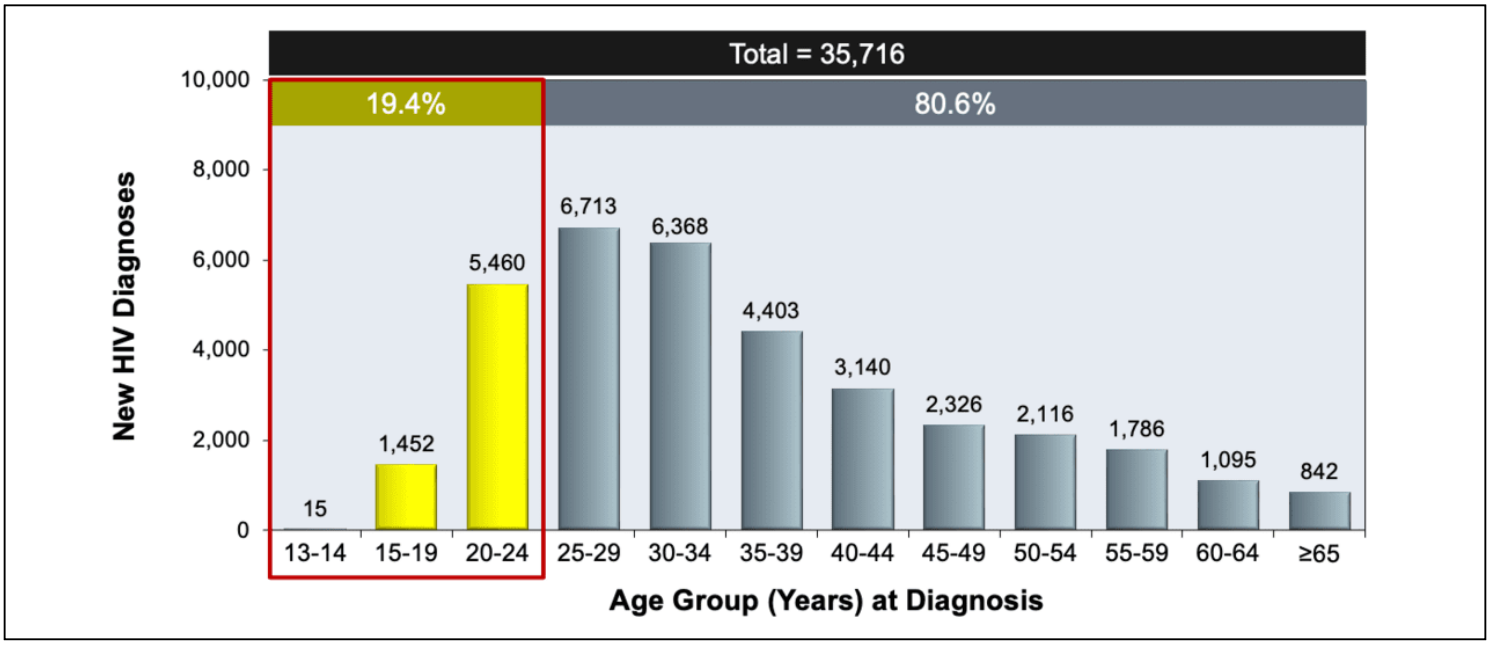

Figure 3 (Image Series) - HIV Transmission Categories for Youth (Image Series) - Figure 3 (Image Series) - HIV Transmission Categories for Youth
Image 3A: Males with Diagnosed HIV, United States, 2021

Source: Centers for Disease Control and Prevention. Diagnoses of HIV infection in the United States and dependent areas, 2021. HIV Surveillance Report, 2021; vol. 34. Published May 2023.

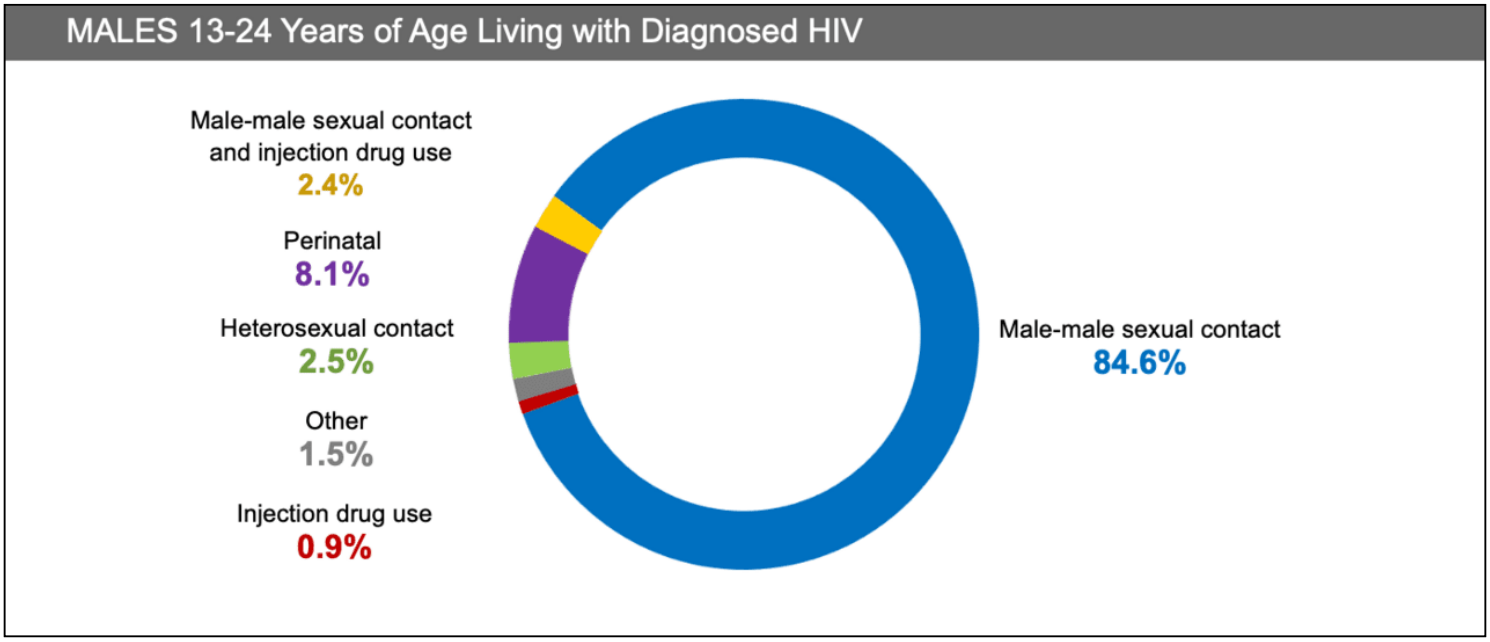

Figure 3 (Image Series) - HIV Transmission Categories for Youth
Image 3B: Females with Diagnosed HIV, United States, 2021

Source: Centers for Disease Control and Prevention. Diagnoses of HIV infection in the United States and dependent areas, 2021. HIV Surveillance Report, 2021; vol. 34. Published May 2023.

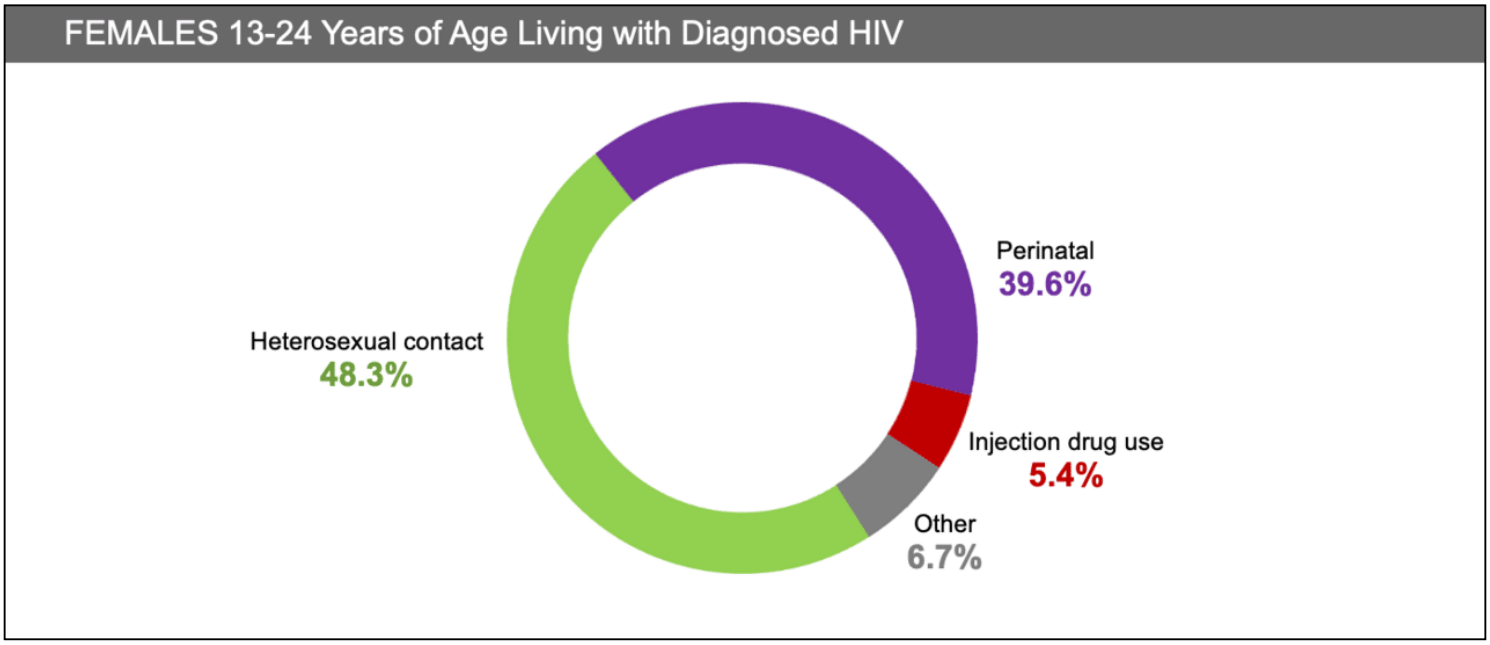

Figure 3 (Image Series) - HIV Transmission Categories for Youth
Image 3C: New HIV Diagnosis in Males, United States, 2021

Source: Centers for Disease Control and Prevention. Diagnoses of HIV infection in the United States and dependent areas, 2021. HIV Surveillance Report, 2021; vol. 34. Published May 2023.

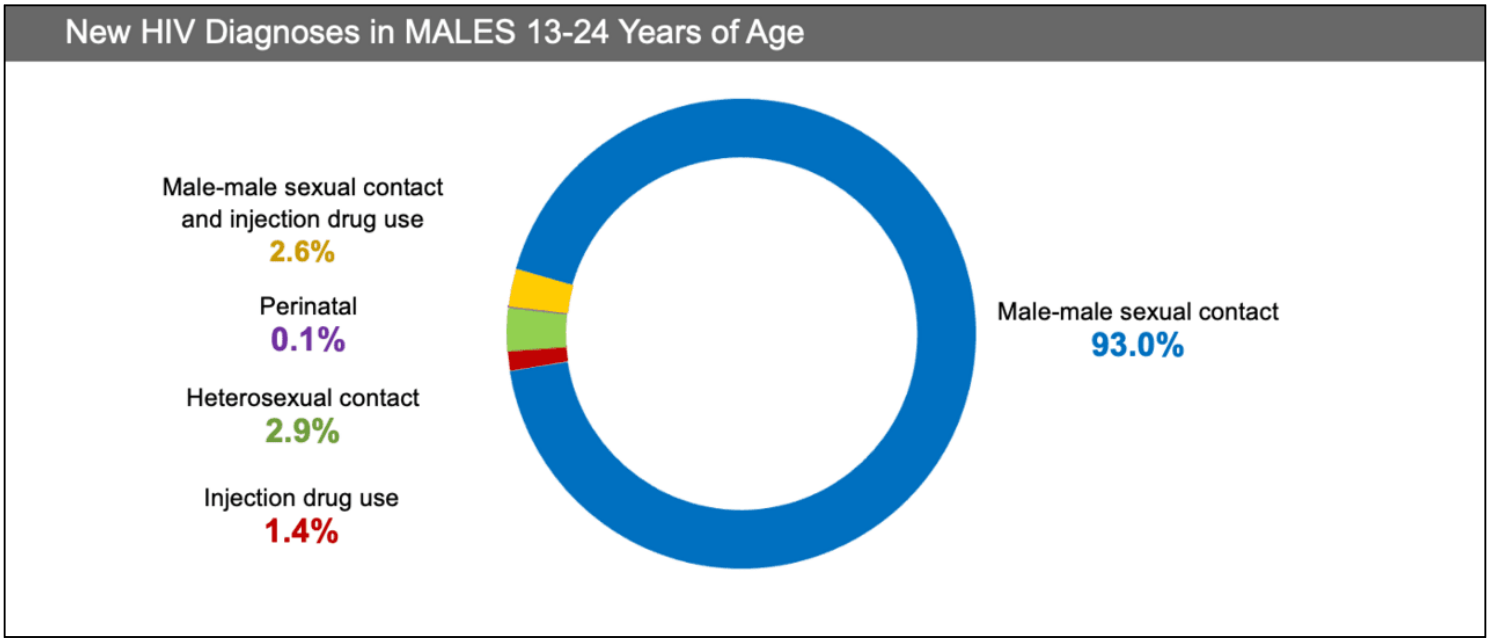

Figure 3 (Image Series) - HIV Transmission Categories for Youth
Image 3D: New HIV Diagnosis in Females, United States, 2021

Source: Centers for Disease Control and Prevention. Diagnoses of HIV infection in the United States and dependent areas, 2021. HIV Surveillance Report, 2021; vol. 34. Published May 2023.

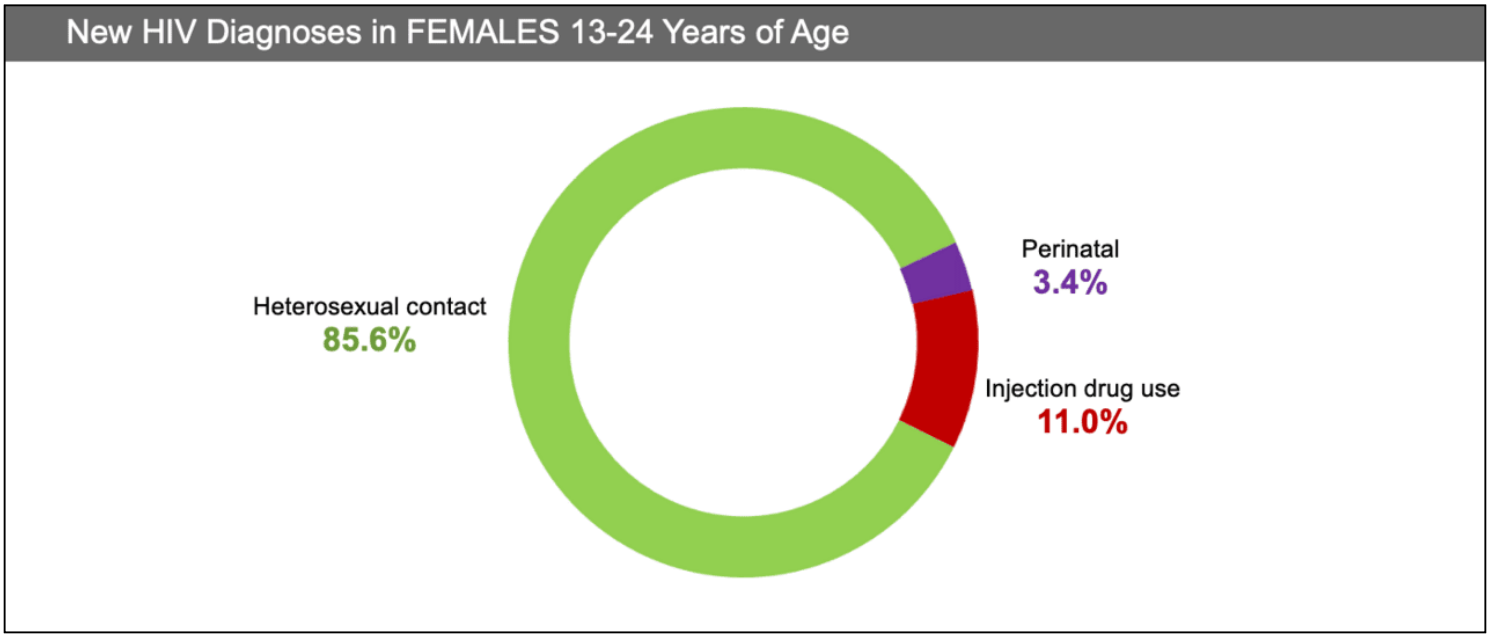

Figure 4 New HIV Diagnoses in Adolescents and Young Adults, by Race/Ethnicity, United States, 2020

This graphic shows the estimated number of adolescents and young adults living with newly diagnosed HIV infection in the United States in 2020, based on race/ethnicity. Note the number of Black youth newly diagnosed with HIV outnumbers White youths by more than 3-fold.

Source: Centers for Disease Control and Prevention. Diagnoses of HIV infection in the United States and dependent areas, 2020. HIV Surveillance Report, 2022; vol. 33:1-143. Published May 2022.

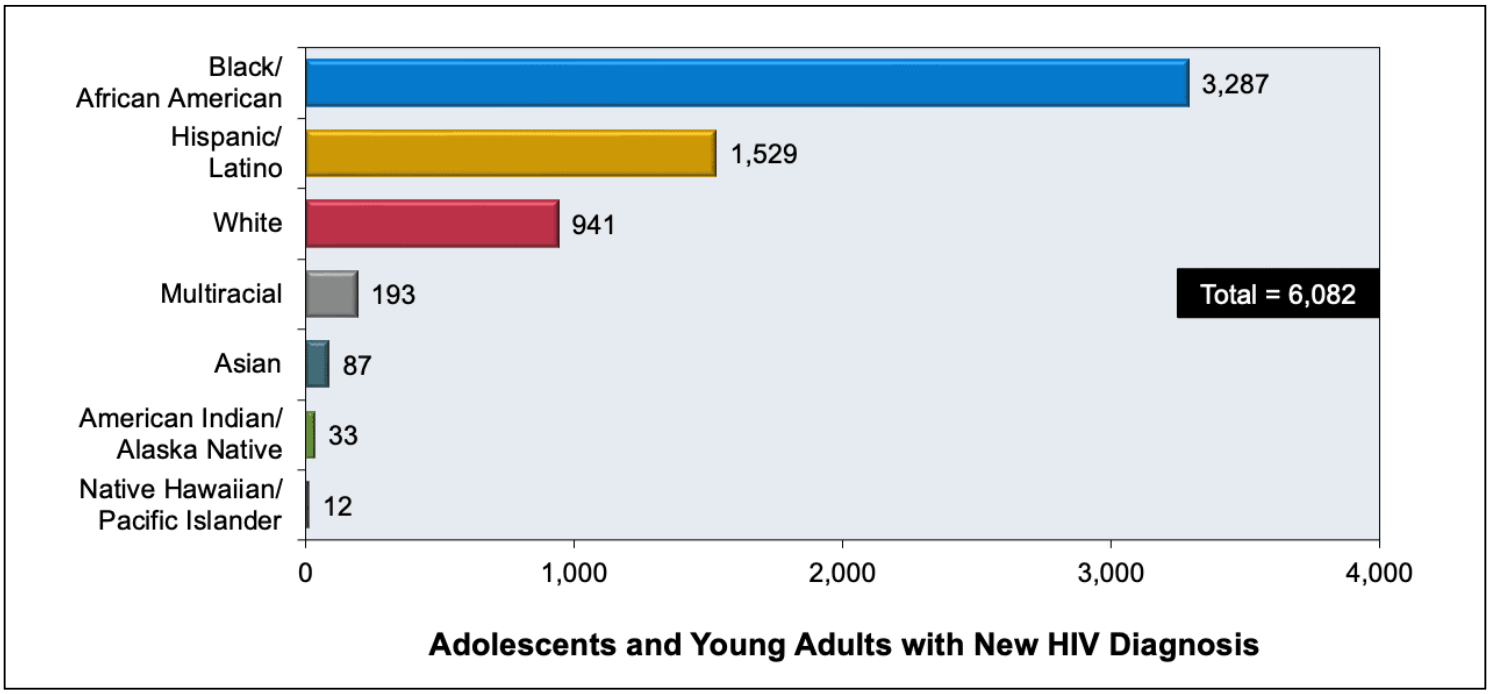

Figure 5 Proportion of Persons with HIV Unaware of HIV Status, by Age Group, United States, 2021

Source: Centers for Disease Control and Prevention. Estimated HIV Incidence and Prevalence in the United States, 2017–2021. HIV Surveillance Supplemental Report. 2023;28(3). Published May 2023.

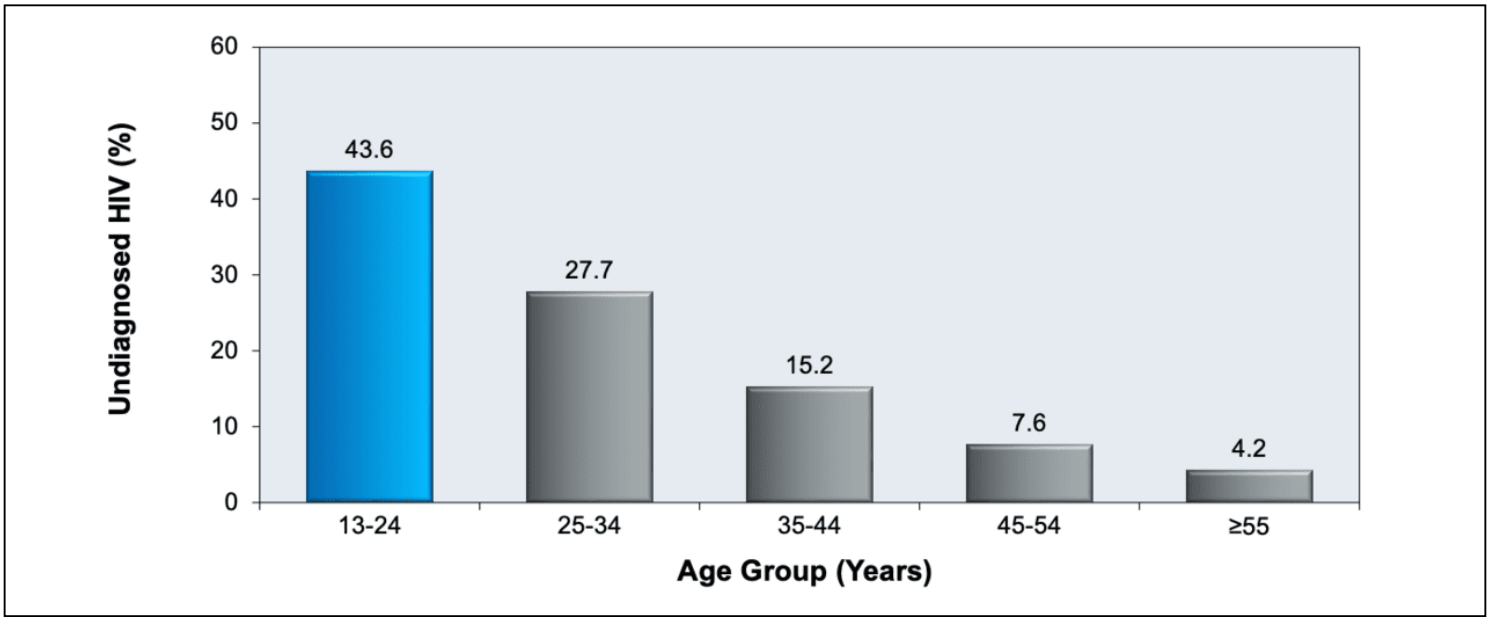

Figure 6 Youth Risk Behavior Survey (YRBS) HIV Test Settings for Young Adults

This graphic shows the test setting for young adults ever tested for HIV. If more than one HIV test was obtained, the setting where the last testing occurred was used. The data was obtained from the National Youth Risk Behavior Survey (YRBS) and Behavioral Risk Factor Surveillance System (BRFSS).

Source: Van Handel M, Kann L, Olsen EO, Dietz P. HIV Testing Among US High School Students and Young Adults. Pediatrics. 2016;137:e20152700.

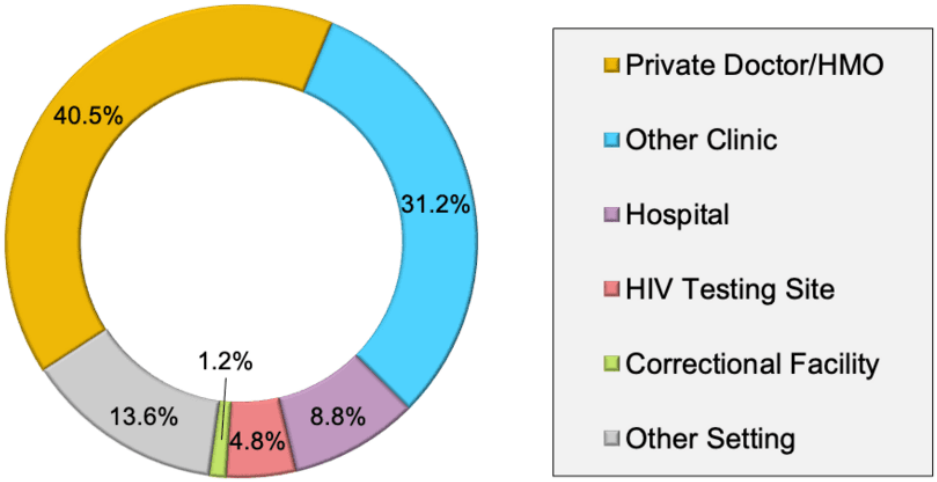

Figure 7 HIV Continuum of Care, by Age Group, United States, 2021

Source: Centers for Disease Control and Prevention. Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data—United States and 6 Dependent Areas, 2021. HIV Surveillance Supplemental Report. 2023;28(No. 4). Published May 2023.

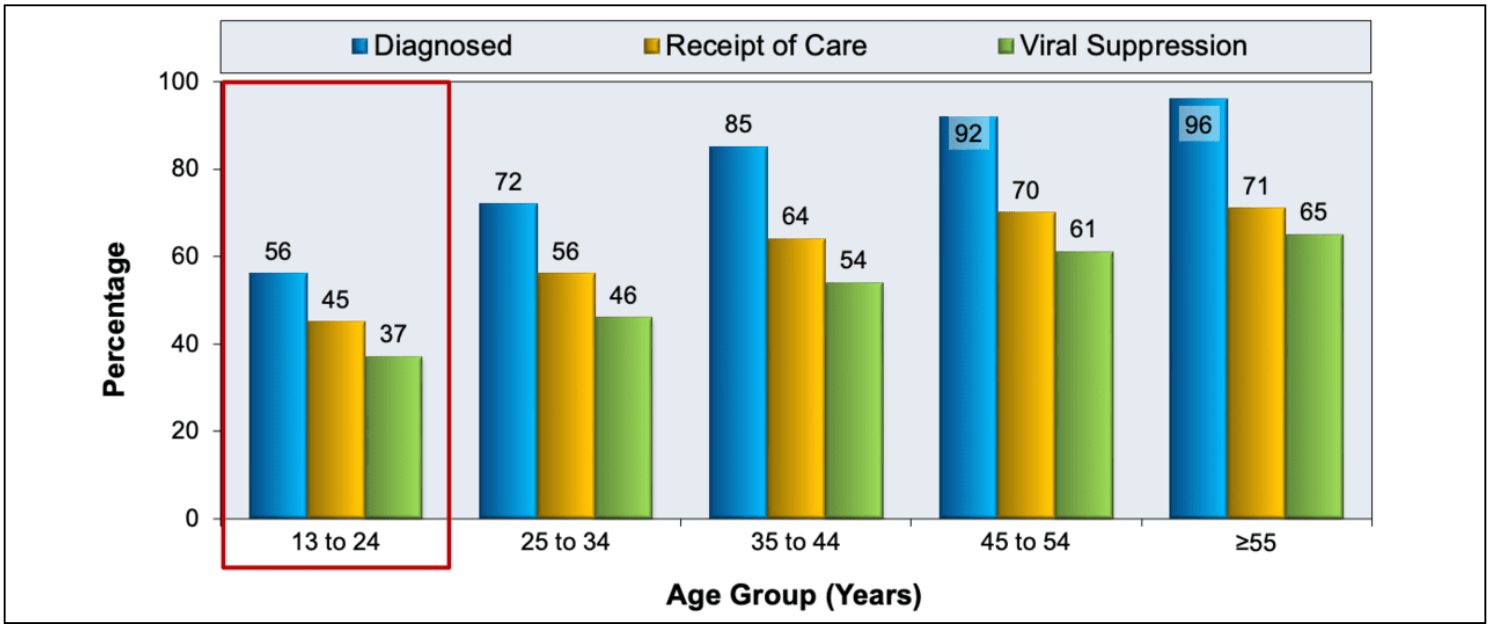

Figure 8 Tenofovir diphosphate Levels During 48 Weeks of PrEP in ATN 113 Study

Source: Hosek SG, Landovitz RJ, Kapogiannis B, et al. Safety and Feasibility of Antiretroviral Preexposure Prophylaxis for Adolescent Men Who Have Sex With Men Aged 15 to 17 Years in the United States. JAMA Pediatr. 2017;171:1063-1071.

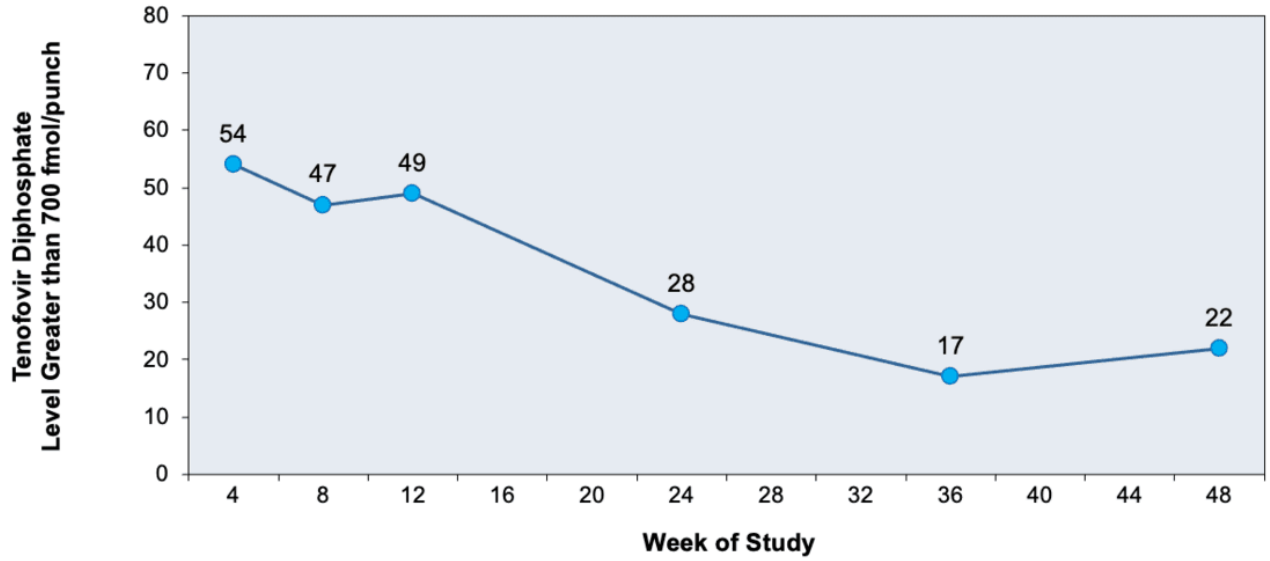

Figure 9 Sexually Transmitted Infections in Youth in IMPAACT P1074

The International Maternal Pediatric Adolescent AIDS Clinical Trials (IMPAACT) P1074 observational cohort study followed 1,042 adolescents and young adults ages 13-24 years and determined rates of sexually transmitted infections (STIs) and compared these rates based on mode of HIV acquisition.

Source: Camacho-Gonzalez AF, Chernoff MC, Williams PL, et al. Sexually Transmitted Infections in Youth With Controlled and Uncontrolled Human Immunodeficiency Virus Infection. J Pediatric Infect Dis Soc. 2017;6:e22-e29.

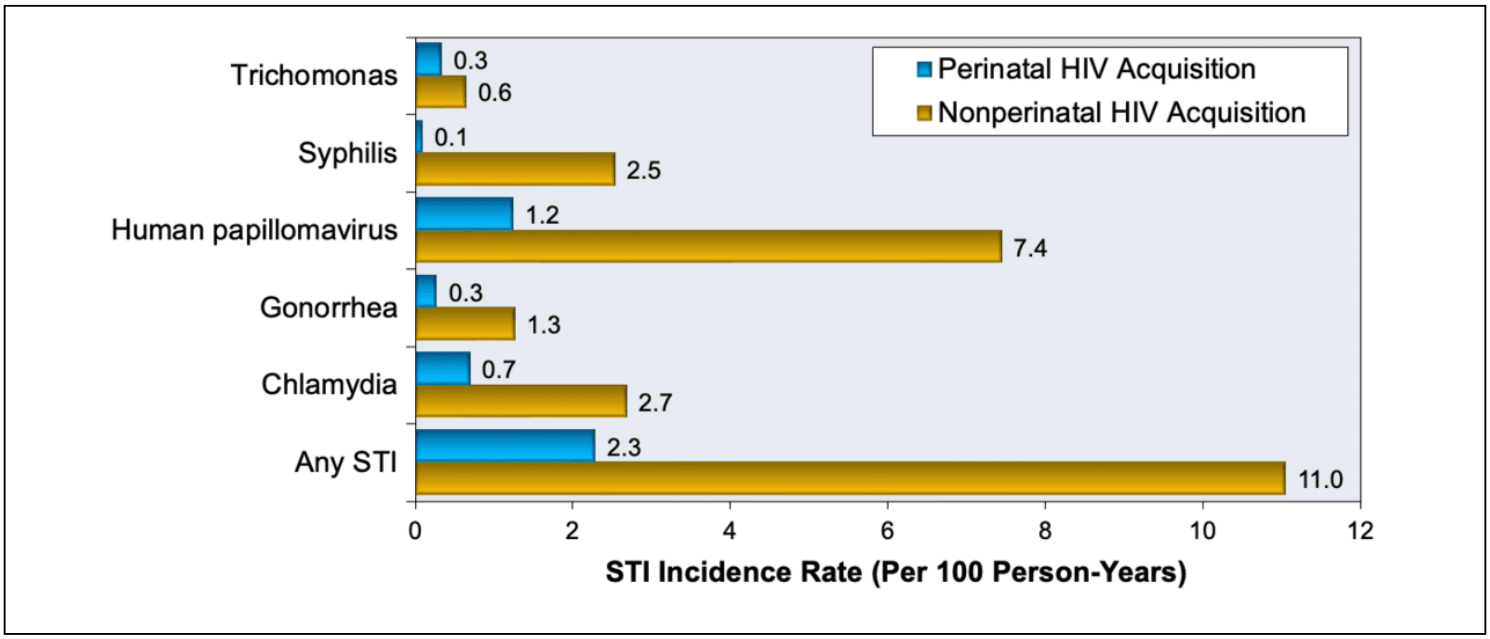

Figure 10 Sexual Activity Among Youth with HIV Aged 12-26 Years in ATN Sites, 2009-2012

Abbreviations: ATN = Adolescent Medicine Trials Network for HIV/AIDS Interventions

Source: Kahana SY, Fernandez MI, Wilson PA, et al. Rates and correlates of antiretroviral therapy use and virologic suppression among perinatally and behaviorally HIV-infected youth linked to care in the United States. J Acquir Immune Defic Syndr. 2015;68:169-77.

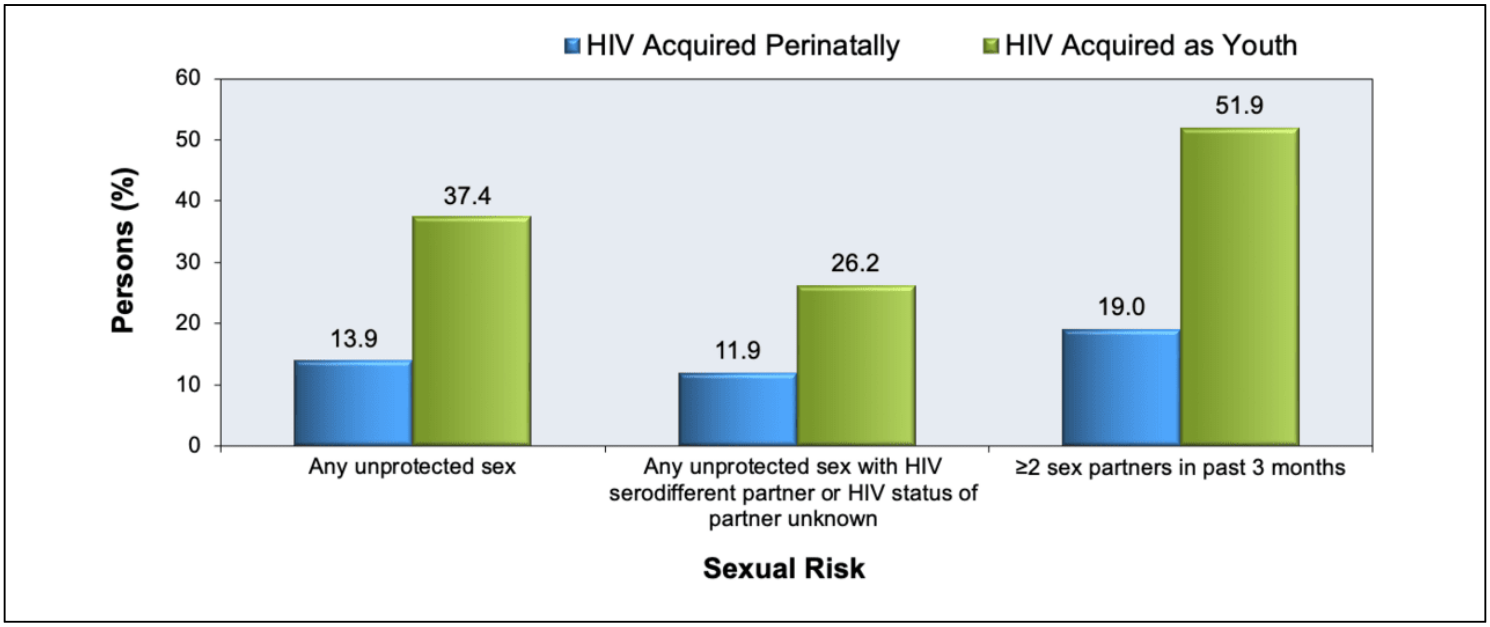

Table 1.

Sexual Maturity Rating (Tanner Staging) in Adolescents

			Female				**Male**		
Stage	Age Range (years)	Breast Growth	Pubic Hair Changes	Other changes	Age Range (years)	Testes growth	Penis growth	Pubic hair growth	Other changes
I	0-15	Pre-adolescent	None	Pre-adolescent	0-15	Pre-adolescent testes (≤2.5 cm)	Pre-adolescent	None	Pre-adolescent
II	8-15	Breast budding (thelarche); areolar hyperplasia with small amount of breast tissue	Long downy pubic hair near the labia, often appearing with breast budding or several weeks or months later	Peak growth velocity often occurs soon after stage II	10-15	Enlargement of testes; pigmentation of scrotal sac	Minimal or no enlargement	Long downy hair, often appearing several months after testicular growth; variable pattern noted with pubarche	Not applicable
III	10-15	Further enlargement of breast tissue and areola, with no separation of their contours	Increase in amount and pigmentation of hair	Menarche occurs in 2% of girls late in stage III	1½–16.5	Further enlargement	Significant enlargement, especially in diameter	Increase in amount; curling	Not applicable
IV	10-17	Separation of contours; areola and nipple form secondary mound above breasts tissue	Adult in type but not in distribution	Menarche occurs in most girls in stage IV, 1–3 years after thelarche	Variable: 12–17	Further enlargement	Further enlargement, especially in diameter	Adult in type but not in distribution	Development of axillary hair and some facial hair
V	12.5-18	Large breast with single contour	Adult in distribution	Menarche occurs in 10% of girls in stage V.	13–18	Adult in size	Adult in size	Adult in distribution (medial aspects of thighs; linea alba)	Body hair continues to grow and muscles continue to

			Female				**Male**		
Stage	Age Range (years)	Breast Growth	Pubic Hair Changes	Other changes	Age Range (years)	Testes growth	Penis growth	Pubic hair growth	Other changes
									increase in size for several months to years; 20% of boys reach peak growth velocity during this period

Source:

- WHO Guidelines Approved by the Guidelines Review Committee. Annex H. Sexual Maturity Rating (Tanner Stage) in Adolescents. Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access: Recommendations for a Public Health Approach: 2010 Revision. [WHO]

Table 2. **Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV**

Recommended Initial Regimens for Most People with HIV

Recommended regimens are those with demonstrated durable virologic efficacy, favorable tolerability and toxicity profiles, and ease of use. Choice of antiretroviral therapy during pregnancy should be guided by recommendations from the Perinatal Guidelines.

For people who do NOT have a history of long-acting cabotegravir use as HIV PrEP, the following regimens are recommended:

INSTI + 2 NRTIs:

- Bictegravir-tenofovir alafenamide-emtricitabine (AI)
- Dolutegravir-abacavir-lamivudine (AI)—only for individuals who are **HLA-B*5701 negative and without chronic HBV coinfection**
- Dolutegravir plus (tenofovir alafenamide or tenofovir DF)[a] plus (emtricitabine or lamivudine) (AI)

INSTI + 1 NRTI

- Dolutegravir-lamivudine (AI)—except for individuals with HIV RNA >500,000 copies/mL, HBV coinfection, or when antiretroviral therapy is to be started before the results of HIV genotypic resistance testing for reverse transcriptase or HBV testing are available

For people with HIV and a history of using long-acting cabotegravir as HIV PrEP, integrase genotypic drug resistance testing should be done before the start of antiretroviral therapy. If treatment is begun prior to the results of genotypic testing, the following regimen is recommended:

Boosted PI + 2 NRTIs:

- Darunavir (boosted with cobicistat or ritonavir) plus (tenofovir alafenamide or tenofovir DF)[a] plus (emtricitabine or lamivudine)—pending the results of the genotype test (AIII).

Abbreviations: INSTI = integrase strand transfer inhibitor; NRTI = nucleoside reverse transcriptase inhibitor
[a]Tenofovir alafenamide and tenofovir DF are two forms of tenofovir approved by the FDA. Tenofovir alafenamide has fewer bone and kidney toxicities than tenofovir DF, whereas tenofovir DF is associated with lower lipid levels. Safety, cost, and access are among the factors to consider when choosing between these drugs.

Rating of Recommendations: A = Strong; B = Moderate; C = Optional
Rating of Evidence: I = Data from randomized controlled trials; II = Data from well-designed nonrandomized trials, observational cohort studies with long-term clinical outcomes, relative bioavailability/bioequivalence studies, or regimen comparisons from randomized switch studies; III = Expert opinion

Source:

- Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in adults and adolescents with HIV. Department of Health and Human Services. What to start: initial combination regimens for people with HIV. September 21, 2022. [HIV.gov]

Table 3. **Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection**

Evidence-Based Approaches for Monitoring Medication Adherence

Routine Assessment of Medication Adherence in Clinical Care	**Description**
Monitor viral load.	Viral load monitoring should be done more frequently after initiating or changing medications.
Assess quantitative self-report of missed doses.	Ask patient and/or caregiver about the number of missed doses over defined period (1, 3, or 7 days).
Request a description of the medication regimen.	Ask the patient and/or caregiver about the name, appearance, and number of medications and how often the medications are taken.
Assess barriers to medication administration.	Engage the patient and caregiver in dialogue around facilitators and challenges to adherence.
Monitor pharmacy refills.	Approaches include pharmacy-based or clinic-based assessment of on-time medication refills.
Employ telemedicine to monitor and support medication administration.	Telemedicine visits allow remote and often face-to-face contact and provide new opportunities to support families; to visualize ART preparation, handling, and swallowing; and to conduct DOT in the home setting.
Conduct announced and unannounced pill counts.	Approaches include asking patients to bring medications to clinic, home visits, or referral to community health nursing.
Targeted Approaches to Monitor Adherence in Special Circumstances	**Description**
Implement directly observed therapy (DOT) in person and via telemedicine.	Include brief period of hospitalization if indicated.
Measure drug concentration in plasma or dried blood spots.	Measuring drug concentrations can be considered for particular drugs.
Approaches to Monitor Medication Adherence in Research Settings	**Description**
Measure drug concentrations in hair.	Measuring hair drug concentrations can be considered for particular drugs; it provides a good measure of adherence over time.
Use electronic monitoring devices.	Approaches include medication Event Monitoring System [MEMS] caps and Wisepill
Use mobile phone-based technologies.	Approaches include interactive voice response, text messaging, and mobile apps.

Source:

- Panel on Antiretroviral Therapy and Medical Management of Children Living with HIV. Guidelines for the use of antiretroviral agents in pediatric HIV infection. Adherence to antiretroviral therapy in children and adolescents living with HIV. April 11, 2023. [HIV.gov]

Table 4. **Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection**

Strategies for Improving Adherence to Antiretroviral Medications

Initial Intervention Strategies
• Establish trust and identify mutually acceptable goals for care. • Obtain explicit agreement on the need for treatment and adherence. • Identify depression, low self-esteem, substance abuse, or other mental health issues in the child/adolescent and/or caregiver that may decrease adherence. Evaluate and initiate treatment for mental health issues before starting antiretroviral drugs, if possible. • Determine whether the child is aware of their HIV status. Consider talking to the child's caregivers about disclosing this information to the child in a developmentally appropriate way. • Identify family, friends, health team members, and others who can support adherence. • Educate patient and family about the critical role of adherence in therapy outcome including the relationship between partial adherence and resistance and resistance and potential impact on future drug regimen choices. Develop a treatment plan that the patient and family understand and to which they feel committed. • Identify barriers—such as co-pays and insurance access—related to medication access to help prevent interruptions in antiretroviral therapy. • Schedule a home visit or telemedicine visit to review medications with the patient and family to make specific plans for taking medications as prescribed and supporting adherence. Assist them to arrange for administration in day care, school, and other settings, when needed. Consider

home delivery of medications. • Establish readiness to take medication through practice sessions or other means. • Schedule a home or telemedicine visit to review medications and determine how they will be administered in the home setting. • Consider a brief period of hospitalization at start of therapy in selected circumstances for patient education and to assess tolerability of medications chosen. • In certain circumstances, consider a brief period of hospitalization at the start of therapy for patient education and to assess the tolerability of the chosen medication.
Medication Strategies
• Choose the simplest regimen possible, reducing dosing frequency and number of pills. • When choosing a regimen, consider the daily and weekly routines and variations in patient and family activities. • Choose the most palatable medicine possible (pharmacists may be able to add syrups or flavoring agents to increase palatability). • Choose drugs with the fewest adverse effects; provide anticipatory guidance for management of adverse effects. • Simplify food requirements for medication administration. • Prescribe drugs carefully to avoid adverse drug-drug interactions. • Assess pill-swallowing capacity and offer pill-swallowing training and aids (e.g., pill swallowing cup, pill glide). Adjust pill size as needed. • Choose an antiretroviral regimen with a high genetic barrier to resistance, when available, if there are concerns about adherence.
Follow-Up Intervention Strategies
• Have more than one member of the multidisciplinary team monitor adherence at each visit and in

between visits by telephone, email, text, and social media, as needed.
- Provide ongoing support, encouragement, and understanding of the difficulties associated with maintaining adherence to daily medication regimens.
- Use patient education aids including pictures, calendars, and stickers.
- Encourage use of pill boxes, reminders, alarms, and timers—such as the CDC's Every Dose, Every Day (E2D2) Toolkit and App.
- Provide follow-up clinic visits, telephone calls, and text messages to support and assess adherence.
- Provide access to support groups, peer groups, or one-on-one counseling for caregivers and patients, especially for those with known depression or drug use issues that are known to decrease adherence.
- Provide pharmacist-based adherence support, such as medication education and counseling, blister packs, refill reminders, automatic refills, and home delivery of medications.
- Consider directly observed therapy at home, in the clinic, or in selected circumstances, during a brief inpatient hospitalization.
- Consider gastrostomy tube use in selected circumstances.
- Information on other interventions to consider can be found at http://www.cd c.gov/hiv/prevention/research/compendium/ma/complete.html

Source:

- Panel on Antiretroviral Therapy and Medical Management of Children Living with HIV. Guidelines for the use of antiretroviral agents in pediatric HIV infection. Adherence to antiretroviral therapy in children and adolescents living with HIV. April 11, 2023. [HIV.gov]

Table 5. **Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection**

Discrepancies Between What Adolescents Want Compared to What Adolescents Experienced

What Adolescents Want	What Adolescents Experience
Relationship with primary care provider who: • Knows them and cares about their health; • Responds to them as individuals and treats them with respect; • Can be accessed on a regular basis; and • Can talk to about issues that are important to adolescents.	• Lack of an established primary care provider • Lack of understanding and respect from their primary care provider • Barriers to accessing a primary care provider • Insufficient opportunities to talk with primary care provider
Comprehensive care where physical, mental, vision and dental health care needs are met.	• Concerns about privacy and sharing information between providers • Limited selection of providers and care
Confidentiality assurances and protections	• Lack of knowledge of existing confidentiality rights and protections for adolescents • Barriers to having time alone with primary care providers

Source:

- Tebb KP, Pica G, Peake K, Diaz A, Brindis CD. Adolescent and Health Professional Perspectives on the Medical Home: Improving Health Care Access and Utilization Under the Affordable Care Act: Philip R. Lee Institute for Health Policy Studies and Division of Adolescent and Young Adult Medicine, Department of Pediatrics, University of California, San Francisco; July 2016. [Health Policy Brief]